

# Health Services Transitions:

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## Processes & Perspectives

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# Presentation Overview

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- Welcome/Sharing your Transition Experience
- Health Care Transitions (HCT)
- Differences of Pediatric and Adult Health Care Systems
- Current State of HCT
- Barriers & Factors influencing HCT

# Presentation Overview cont.

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- Potential Outcomes of Unsuccessful HCT
- Models of Successful HCT
- Changing Roles of Professionals, Parents, and Youth
- Supporting HCTs of Youth with Significant Cognitive Disabilities
- Transition Tools & Resources

# Operational Definition of Health Care Transition

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A purposeful planned process that supports adolescents and young adults with chronic health conditions and disabilities to move from child-centered (pediatric) to adult-oriented health-care practices, providers, programs, and facilities.

Reiss & Gibson, 2004

# What we know about Health Care Transitions (HCT)

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- ❑ HCT critical but only part of becoming adult
- ❑ HCT involves:
  - ❑ Long-term planning
  - ❑ Long-term skill development
- ❑ Pediatric and adult medical systems two distinct cultures
- ❑ Interpersonal relationships critical

**Differences of Pediatric  
and**



**Adult Health Care  
Systems**

# Pediatric versus Adult

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- Family-focus; parent as decision maker
- Parent as expert partner
- Supports development of skills; developmental orientation
- Patient-focus, confidentiality
- Physicians as expert
- Requires patient to be autonomous and competent; to function independently

# Pediatric versus Adult

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- Multidisciplinary/ team model with support services
- Informal, relaxed, warm, optimistic interpersonal
- Specialist consultation model; minimal support
- Business-like, formal and judgmental



# Pediatric versus Adult

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- Child as whole person within family context
- Flexible, individualized treatment approach
- Active oversight and advocacy
- Primary focus on disease process
- Standard treatment approach; procedure and lab-based
- Minimal oversight; patient responsibility

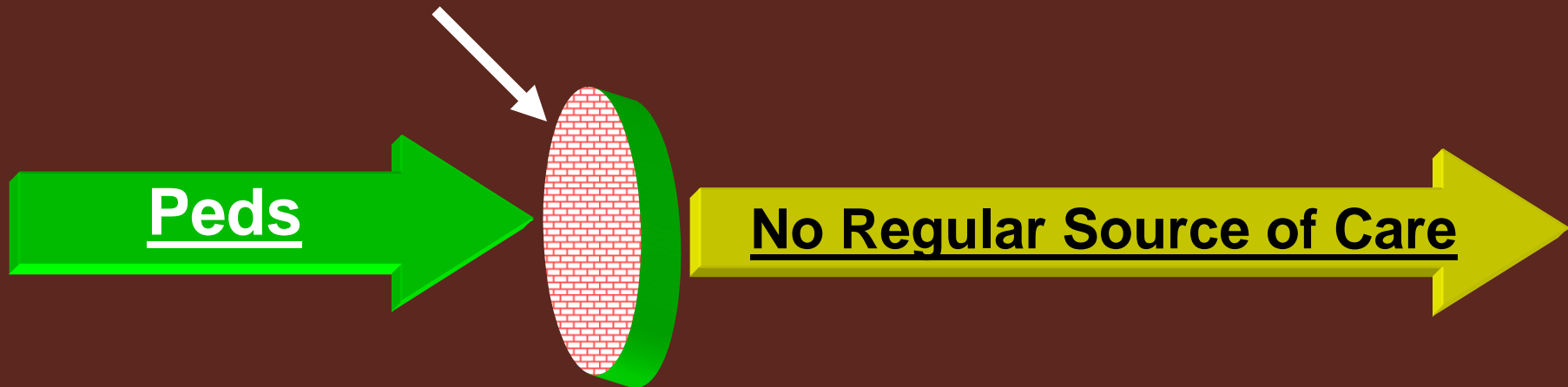
# Current State of Health Care Transitions (HCTs)



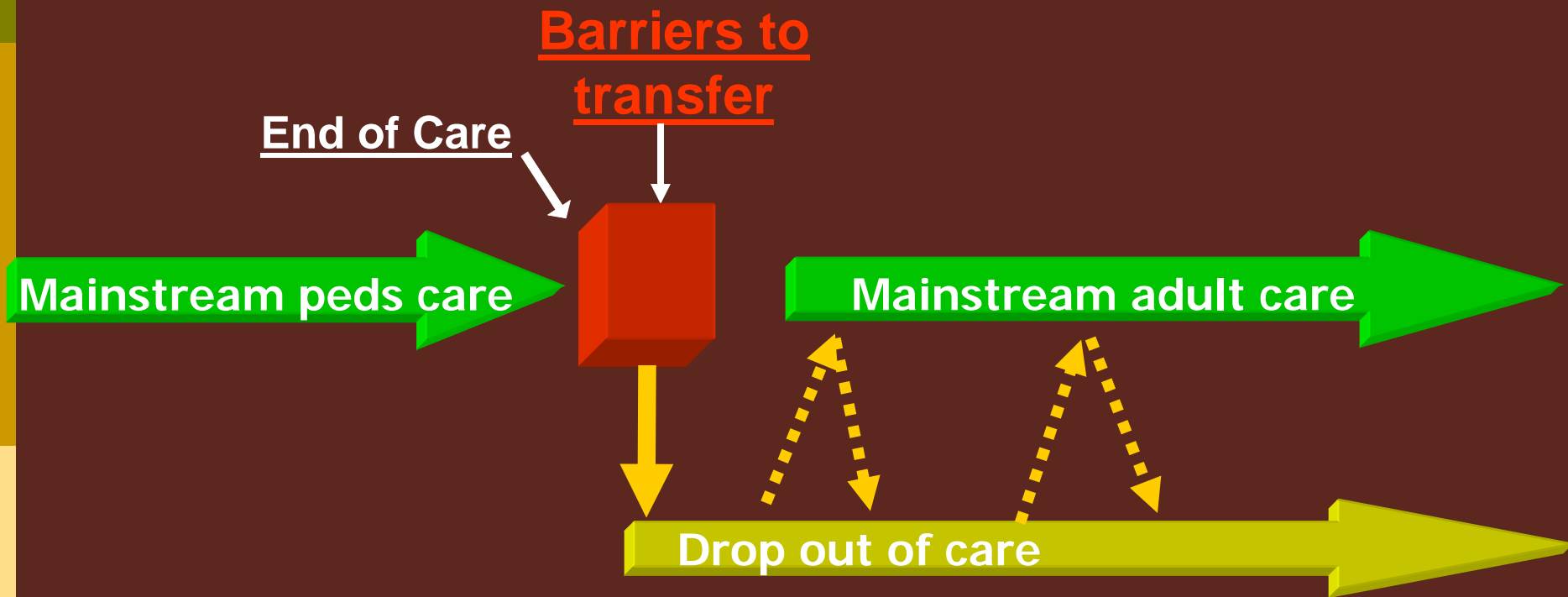
No HCT services → youth drop out of regular care after leaving pediatrics

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Barriers to transfer

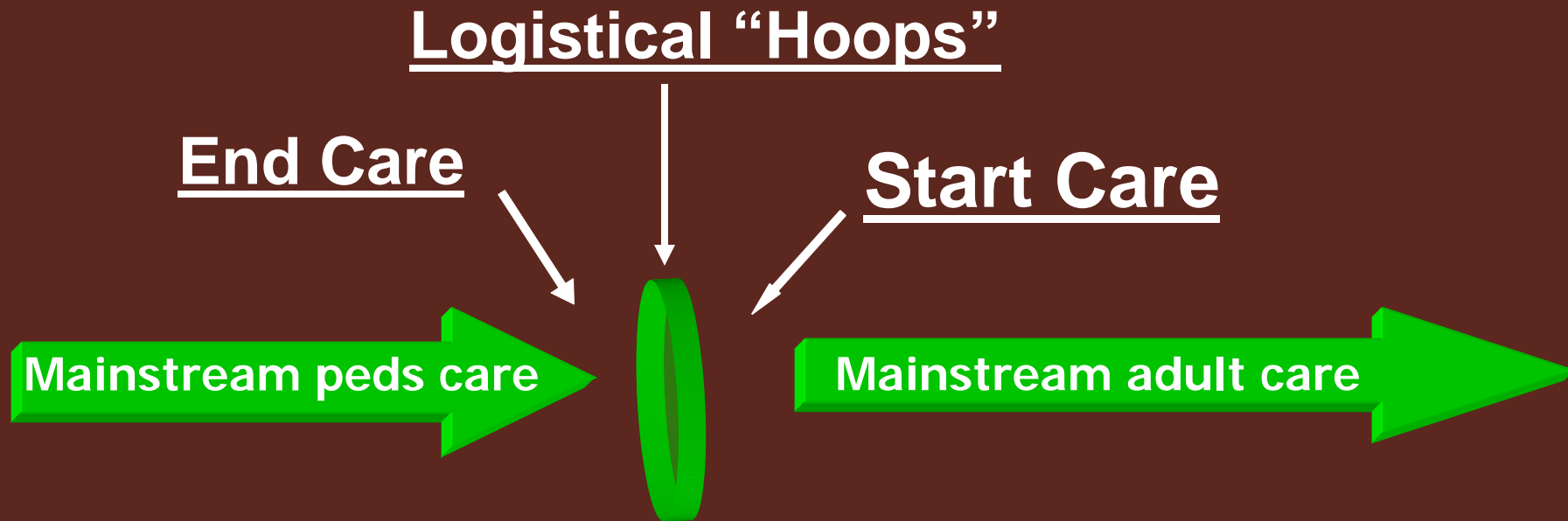


# No HCT Services youth drop out of regular care, but use adult services intermittently



No HCT services  youth jump through logistical “hoops” and start adult care

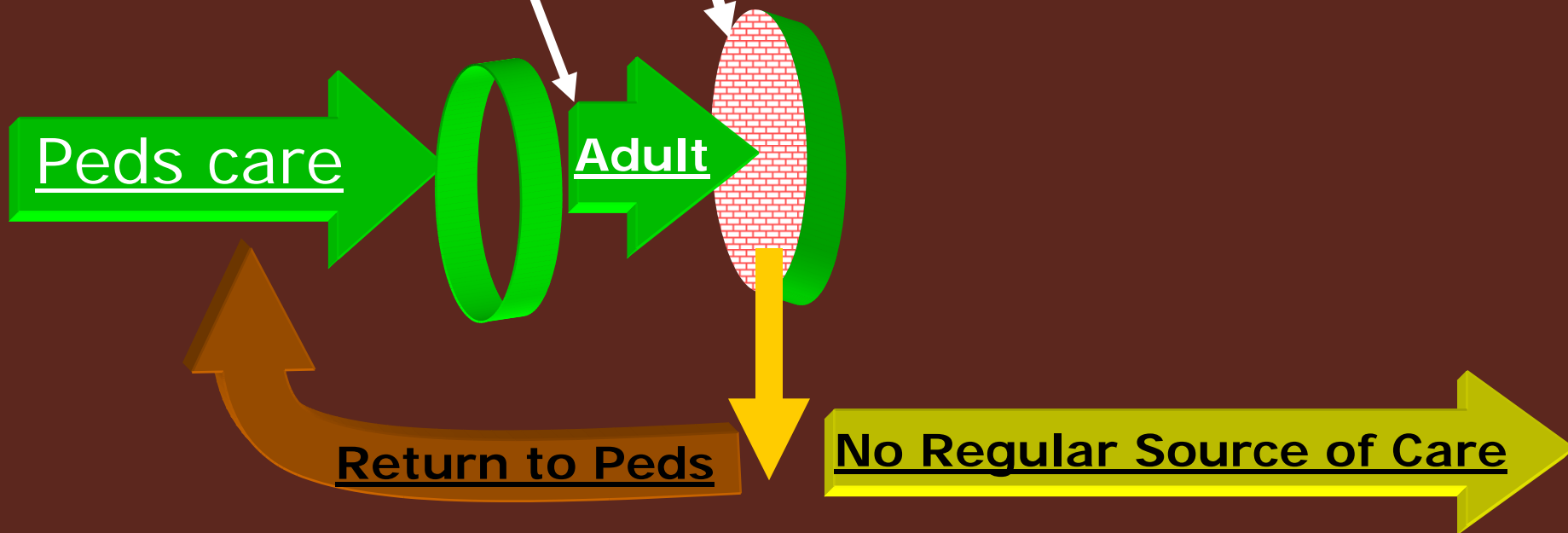
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No HCT services → youth start adult care,  
but do not continue with adult providers

Barriers to integration  
into adult care

Start of Care



# Barriers and Factors that Inhibit Smooth Health Care Transitions



# Health System Factors

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- No mechanism to transition youth, as a group
- Transfer not based on readiness or need
- Little networking among pediatric and adult health and related services (esp. MD's)



# Health System Factors

(cont.)

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- Limited capacity of adult medicine in childhood onset conditions
- Differences in culture & practices in pediatric and adult medicine

# Health Policy Factors

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- Differences in financing and reimbursement of pediatric and adult health care
- No entity is responsible for improving systems for growing population of young adults with disabilities and SHCN (like Title V CSHCN Program)

# Social Environment Factors

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- “Full adult” status not achieved by most until late 20’s (education, work, family formation, independent living, finances)

# Social Environment Factors

(cont.)

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- Age-limits of health providers, facilities, programs & financing are out of sync with social reality of “emerging adulthood” status (age 18-30)

# Youth, Young Adult, & Family Factors

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- Youth & families not aware that move to adult system may be difficult
- Youth & families often not prepared for move

# Youth, Young Adult & Family Factors (cont.)

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- Young adults (& family) have limited capacity to interact successfully with adult system when transferred (knowledge & skills)

# Potential Outcomes of Unsuccessful Health Care Transitions



# Health Risks

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- ❑ Adult primary and specialty care providers may lack interest in and experience with “pediatric” disease in adult life
- ❑ Inconsistency and discontinuity of care
- ❑ Reduction in amount, duration, and scope of health care services and supports



# Health Risks cont.

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- ❑ Adult system lacks familiarity with associated health risks (e.g. increased risk for cancer)
- ❑ Loss of knowledge-base regarding the “natural course” of the individual’s condition

# Stresses from Transfer

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- ❑ Transfer experienced as rejection
- ❑ Transfer causes feelings of grief and loss
- ❑ Loss of peer group

# Stresses from Transfer cont.

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- ❑ Loss of formal and informal social supports for youth and their families
- ❑ Parents feel alienated
- ❑ Culture shock

# Demands from Transfer

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- ❑ Young adults (YAs) feel overwhelmed by new responsibilities: self-care, medical decision making, self-monitoring, self-advocacy etc.
- ❑ YAs need to unlearn successful pediatric adaptive behaviors and strategies

# Demands from Transfer (cont.)

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- YAs need to learn new “adult system” behaviors
- YAs confronted with “realities” of increasing morbidity and early death

# Stress on Adult System

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- Adult providers need to acquire new knowledge and skills to care for young adults with “childhood onset” conditions
- YA patients may be challenging both clinically and interpersonally

# Stress on Adult System (cont.)

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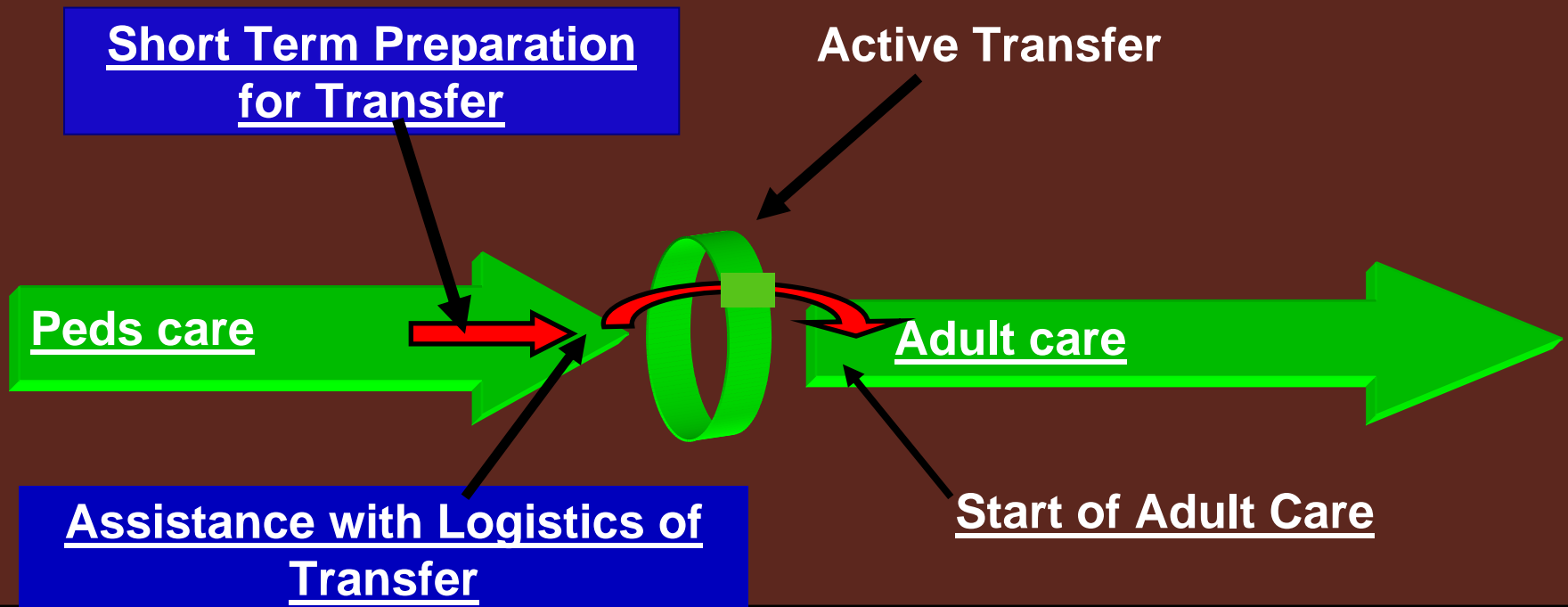
- ❑ YA patients may be uninsured or have public insurance (lower reimbursement rate)
- ❑ YA patients may have limited competencies

# Models of Successful Health Care Transitions





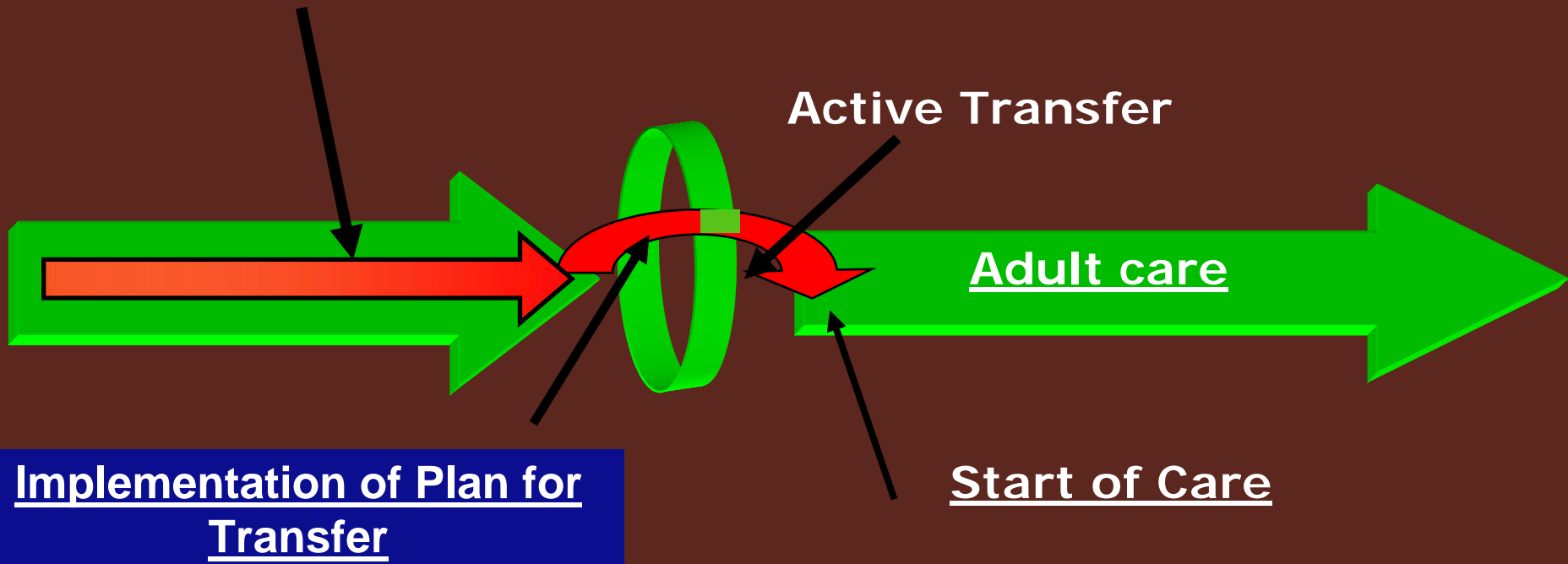
# Short Term HCT Services, including Support with Transfer, and Start Adult Care



# Long Term HCT Services, Transferred To and Start Adult Care

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Long Term Preparation  
for Transfer



**Changing Roles of  
Professionals, Parents, &**



**Youth, in the  
Transition Process**

Stage	Professional	Parent	Child/ Young Adult
1 (Child 6-11)	<u>Lead</u> responsibility	<u>Participates</u> & <u>Provides</u> care	<u>Receives</u> care
2 (Young Adolescent 12-14)	<u>Partner</u> Gives guidance & support	<u>Full Partner</u> Guides & manages	<u>Participates</u> in care & decision making
3 (Adolescent 15-17)	<u>Consultant</u>	<u>Supervisor</u> Shared decision making	<u>Manager</u> Shared decision making
4 (Young Adult 18+)	<u>Resource</u>	<u>Consultant</u>	<u>Lead</u> Manages & Supervises

# Working Alliance

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- Professionals, Parents, and Youth work together as an alliance in the transition process
- Professional initiates alliances

# Working Alliance cont.

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- Characteristics of a working alliance:
  - Trust & respect
  - Liking
  - Negotiated goals
  - Negotiated strategies
  - Negotiated roles and responsibilities

# Stage 1: Professionals' Roles

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- Provide framework for promoting child's growth and development
- Identify & acknowledge families' values and priorities
- Affirm child's/family's strengths
- Develop plan based on shared goals

# Stage 1: Professionals' Challenges

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- ❑ Let go of “professional model” of coping
- ❑ Let go of “professional” as only expert
- ❑ Accommodate to family coping
- ❑ Getting “caught in the middle”



# Stage 1: Parents' Roles

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- Identify goals and priorities for newly diagnosed child
- Reexamine goals and priorities for self and family as whole

# Stage 1: Parents' Challenges

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- Letting go of “perfect child”
- Letting go of guilt and blame
- Letting go of notion of “right” roles & responsibilities for mother and father
- Balancing needs of all family members (including couple)
- Keeping/developing vision for future

# Stage 1: Child's Role

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- Child receives care
- May be involved in learning name of his/her condition
- May begin to assist in care

# Stage 1: Child's Challenges

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- May begin to realize his/her differences from other children
- May begin realize his/her limitations

# Stage 1: Promising Practices

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- Parent-to-parent support
- Role models
- Family movement

# Stage 2: Professionals' Roles

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- Inform parents
- Empower parents
- Promote parent effectiveness
- Support evolving working alliance with parents and growing child/youth

# Stage 2: Professionals' Challenges

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- Giving up need to “know best”
- Maintaining high expectations for child and future

# Stage 2: Parents' Roles

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- Promote growing child's/adolescent's autonomy & capacity
- Guide & manage child's/adolescent's care
- Inform and empower
- Support child/adolescent in cognitive, personal, and social development



# Stage 2: Parents' Challenges

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- ❑ Giving up need to “do it all myself”
- ❑ Maintaining high expectations for child's and adolescent's future
- ❑ Begin external shifts in care and support

# Stage 2: Young Adolescents' Roles

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- ❑ Developing capacity and function as a participant in self care and decision making
- ❑ Increased responsibility for self-care
- ❑ Inclusion in decision-making

# Stage 2: Young Adolescents' Challenges

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- ❑ Self-consciousness/anxiety about body shape, growth, and sexuality
- ❑ Concerns about being “normal” and “fitting in”
- ❑ Need to belong to peer group(s)
- ❑ Establishing emotional distance from parents
- ❑ Separating “help” from “support”

# Stage 2: Promising Practices

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- Professional provides guidance in care
- Professional provides support to family
- Care is family driven BUT youth guided

# Stage 2: Promising Practices cont.

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- Family and professionals promote autonomy of young adolescent:
  - Focus on individual's goals, values, interests, skills, and needs
  - Youth makes some decisions about his/her care and life
  - Youth is involved in care
  - Youth is safe and has emergency plan

# Stage 3: Professionals' Roles

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- Professional as a “consultant”
- Deferring decision making to parents and adolescents
- Establishing separate relationship with adolescent
- Anticipatory guidance re: adulthood
  - Work
  - Autonomy
  - Independent living

# Stage 3: Professionals' Challenges

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- ❑ Establishing separate relationship with adolescent (personal barriers, parent barriers)

# Stage 3: Parents' Roles

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- Parents as “supervisors”
- Promoting adolescent’s “self-efficacy”
- Promoting adolescent’s “independence”
- Trusting adolescent in his/her decision-making



# Stage 3: Parents' Challenges

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- ❑ Letting go of “my way is right”
- ❑ Maintaining “life” outside of needs of youth
- ❑ Accommodating to “normal” adolescent development:
  - Adolescent risk taking behavior
  - Adolescent’s need for “privacy”
  - Friends as confidants

# Stage 3: Adolescents' Roles

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- ❑ Developing capacity and function as the manager of self care and decision making
- ❑ Taking responsibility for taking meds, following routine, etc.
- ❑ Making independent decisions about care

# Stage 3: Adolescents' Challenges

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- ❑ Identifying personal assets and liabilities
- ❑ Making decisions and relying on own judgment and personal resources
- ❑ Establishing independent relationships with adults outside the home
- ❑ Having love/intimate relationships

# Stage 3: Promising Practices

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- Allowing adolescents' independence
- Supporting adolescents in establishing relationships with other adults
- Supporting adolescents in their relationships with peers
- Allowing adolescents "safe" learning from mistakes

# Stage 4: Professionals' Roles

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- Resource to young adult

# Stage 4: Parents' Roles

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- Parents are consultants
- Respecting young adult's autonomy
- Providing input and support as requested
- Assisting young adults in making good use of available resources and sources of support
- Focusing on self and new activities

# Stage 4: Parents' Challenges

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- Letting “go”
- Accepting child as an adult
- Focusing on self and new activities

# Stage 4: Young Adults' Roles

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- Taking responsibility for own care
- Making decisions independently
- Taking care of and creating independent adult life



# Stage 4: Young Adults' Challenges

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- ❑ Setting and achieving educational, vocational, and social/personal goals
- ❑ Separating from parents:
  - Being financially independent
  - Living on own
  - Establishing relationship with significant other
- ❑ Establishing a system of mutual supports

**Supporting Transition of**



**Youth with Significant  
Cognitive Disabilities**

# Transition Supports

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- Work with parents on future expectations and goals for adolescents
- Provide developmentally appropriate supports to youth
- Seek out cognitive based opportunities

# Transition Supports

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- Identify future formal and informal supports:
  - Guardianship
  - Trust Funds
  - Identify adult providers trained in providing care to young adults with complex needs/cognitive limitations
  - Identify day/vocational programs
  - Identify socialization opportunities

# Transition Tools &



# Resources

# Transition Plan

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- What does it take to manage the special health care need to stay healthy?

# Transition Plan cont.

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- What are the special skills and/or knowledge necessary for independence and health?
  - What is my child (am I) responsible for now?
  - What does my child (do I) need to learn?
- What tasks will need to be addressed but given to others to carry out?

# Health Care Transition Workbooks\*

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For ages 12-14, 15-17, 18+

- Thinking About Your Future
- Basic Knowledge
- Health Care Practices

\* Reiss and Gibson (2005)



# Health Care Transition Workbooks\* cont.

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- Meds, Tests, Equip & Supplies
- Doctor Visits
- HCT Tasks and Activities
- Transition to Adulthood
- Health Systems

\* Reiss and Gibson (2005)

# Transition Resources

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□ <http://hctransitions.ichp.ufl.edu>

Downloadable workbooks, checklists, videos on HCT

□ [www.transitionmapde.org](http://www.transitionmapde.org)

Downloadable workbooks, checklists, questions to ask adult providers,

Delaware-specific database of adult providers



...if we wait for the  
moment when  
everything,  
absolutely  
everything is ready,  
we shall never begin.  
Ivan Turgenev

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